



Parkinson's Disease: Social and Economic Impact



June 2003

INTRODUCTION

What is Parkinson's Disease?

Parkinson's is a progressive neurodegenerative disease, primarily affecting voluntary, controlled movement. It results from the loss of cells in a part of the brain called the substantia nigra. These cells are responsible for producing the neurotransmitter chemical, dopamine, which acts as a messenger between the cells of the brain that control the body's movements.

Nearly 100,000 Canadians have Parkinson's. The estimated prevalence rate (the number of people living with Parkinson's at any one time) is 100 to 200/100,000 population, with an incidence rate (number of people newly diagnosed each year) of 10 to 20/100,000. Eighty-five percent of those diagnosed are over the age of 65 and that age group is predicted to rise dramatically over the next 30 years from 11.6% to 23.6% of the population, increasing the expected incidence of Parkinson's disease significantly.

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Signs & Symptoms

Parkinson's disease is diagnosed through clinical assessment based on the symptoms described by the patient and a complete neurologic examination by the physician. There are no blood tests or diagnostic imaging currently available to definitively confirm its presence. In some people, diagnosis is made easier by the presentation of the classic signs of a tremor at rest on one side of the body, slowed movements (*bradykinesia*) and stiffness or rigidity. Two of the three must be present to make the diagnosis. Postural instability, a later sign of Parkinson's, is a balance disorder, which can result in frequent falls.

Other symptoms can include depression and anxiety, masked facial features, handwriting difficulties, diminished voice volume and monotone voice, constipation, increase in urinary problems, orthostatic hypotension (low blood pressure upon rising from a seated position), fatigue and sleep disorders, and non-specific sensory symptoms such as numbness, pain, burning sensation and restlessness.

The symptoms of Parkinson's fluctuate throughout the course of the disease and intensify progressively over time. A number of assessment tools are used by clinicians to measure the impact of the disease on the individual, and while it is difficult to establish a "typical" rate for the progression of symptoms, it is safe to say that individuals often experience significant disability 10 to 15 years following diagnosis. Typically the progression is from one-sided symptoms that have little impact on the quality of life to the appearance of symptoms on both sides of the body, to decreasing mobility, and eventual reliance on others for care when the activities of daily living are no longer possible to maintain independently.

Treatments

While there is presently no cure for Parkinson's, there are a number of treatments, both drug and therapy-based, used to help control symptoms and improve the individual's quality of life.

Drug treatment for Parkinson's requires almost constant adjustment over the course of the disease and varies in effectiveness over time. The worldwide cost of medications alone is estimated to be US \$11 billion per year.

According to a recent report in the journal *Neurology*⁽¹⁾, costs for individuals increase three- to five-fold from diagnosis to advanced disease stage. Canadian movement disorder specialists estimate the monthly cost of Parkinson’s medications for the typical Canadian patient at \$1,000⁽²⁾.

The initial goal of drug treatment is to slow progression of the symptoms and to reduce disability without inducing complications over the long term⁽¹⁾. However, with the prolonged use of most currently available drug therapies, adverse effects such as *dyskinesias* (abnormal, uncontrollable, writhing movements of the limbs) or *wearing off*, may develop.

Surgery, including the implantation of deep brain stimulators, is helpful for a number of carefully selected individuals with Parkinson’s. However, because of the cost (estimated at \$15-20,000 per procedure) and the difficulty accessing appropriately qualified and experienced neurosurgeons, many people with Parkinson’s who meet the criteria are unable to undergo this procedure.

Parkinson’s progresses over many years and at different rates for each person. A variety of health care professionals can play a vital role in managing symptoms and the typical person with Parkinson’s may require the help of the following: family physician; neurologist or movement disorder specialist; a Parkinson’s nurse specialist; pharmacist; occupational therapist; physiotherapist; social worker/psychologist; speech and language pathologist; and dietitian.

Although the cause of Parkinson’s is not clear, scientists believe a combination of genetic and environmental factors are involved and they continue to research this area. It is not, however, thought to be

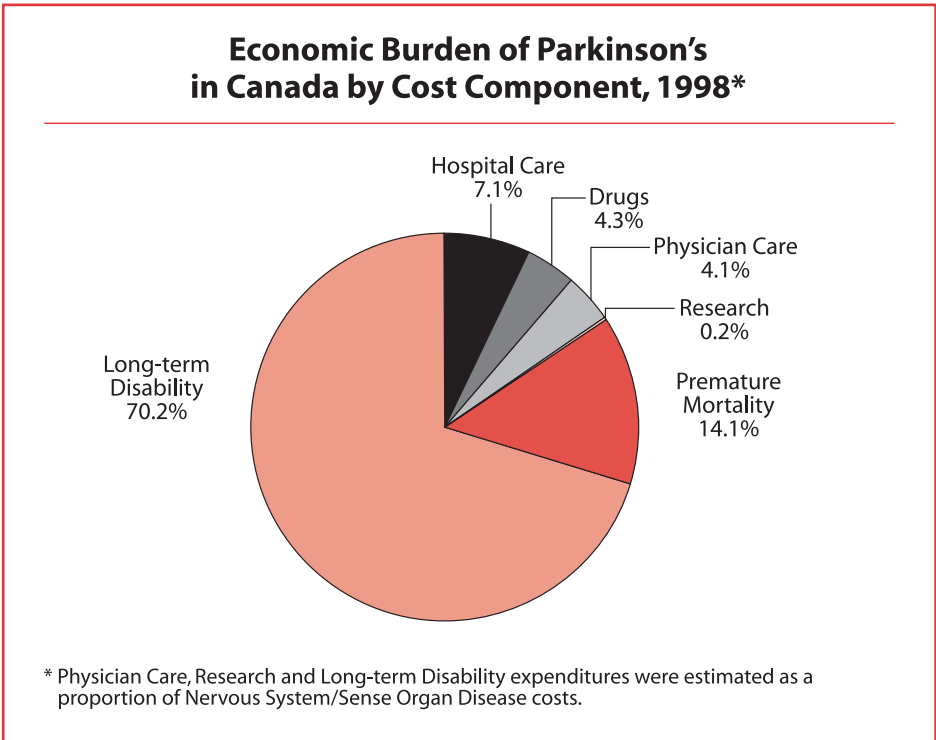
a disease connected to lifestyle choices such as poor eating habits or lack of exercise.

ECONOMIC BURDEN OF PARKINSON’S

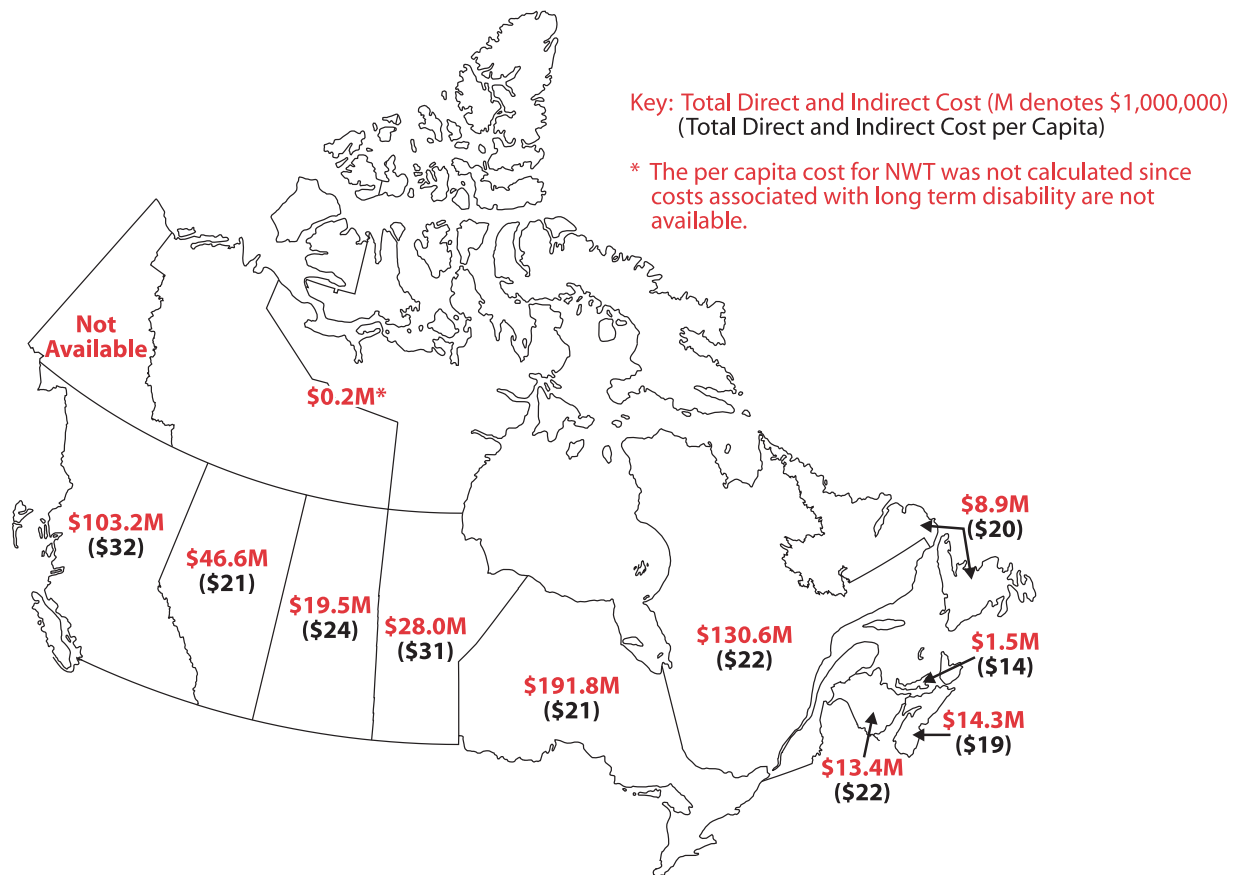
The information on the economic burden of Parkinson’s disease provided in this publication is based on estimates from the Health Canada report, “Economic Burden of Illness in Canada, 1998”, published in late 2002⁽³⁾. The full report estimates the direct and indirect costs of 20 diagnostic categories and 20 diagnostic subcategories for 1998. While the diagnostic category Nervous System/Sense Organ Disease costs have been estimated in previous versions of this report, this is the first time that the report includes Parkinson’s disease as a subcategory of Nervous System/Sense Organ Diseases with specific estimates.

Standard methods were used to calculate direct and indirect costs, the two main components of the economic cost of Parkinson’s disease.

Total cost of Parkinson’s disease: \$558.1 million.



Cost of Parkinson's Disease for 1998 in Canada by Province/Territory



Direct costs comprise those resources used in the prevention, detection and treatment of Parkinson's disease categorized by hospitals, drugs, physicians, and research. These costs include the totality of health expenditures made by Canadians and all levels of government. However, other direct costs borne by patients or other payers (such as costs for transportation to health providers, etc.) are not included.

The indirect costs of Parkinson's disease result from lost production due to disability and premature death. The latter was estimated using the human capital approach — a method based on the number of deaths and the financial value assigned to the remaining potential production of individuals that is now lost as a result of those premature deaths. Other indirect costs, including the value of time lost from work and leisure activities by family members or friends who care for the patient, are not included.

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Highlights from the Economic Burden of Illness in Canada, 1998

- Total cost of illness in Canada in 1998: \$159.4 billion
- Total cost of Nervous System/Sense Organ Diseases: \$8.3 billion
- **Total cost of Parkinson's disease: \$558.1 million** (Males 56.3%, Females 43.4%, 0.3% unspecified)
- Parkinson's Direct costs: \$87.8 million (Males 57.6%, Females 40.2%, 2.2% unspecified)
 - Hospital care: \$39.7 million
 - Drugs: \$24.1 million
 - Physician care: \$23.0 million
 - Research: \$1.0 million
- Parkinson's Indirect costs: \$470.3 million (Males 56.0%, Females 44.0%)
 - Premature mortality: \$78.6 million
 - Long-term disability: \$391.7 million
- **Men** account for 46% of total Nervous System/Sense Organ disease costs and over **55% of total Parkinson's costs**.
- **Seniors** (individuals over the age of 65) account for almost 25% of total Nervous System/Sense Organ disease costs and **90% of total Parkinson's costs**.
- **Over 75% of total Parkinson's disease costs** are incurred in **Quebec, Ontario, and British Columbia**.
- Average **cost per capita** for Parkinson's disease in Canada: **\$23 per year**.

FINDINGS AND IMPLICATIONS

The information in this publication provides a brief overview of the existing national data on the economic and social burden of Parkinson's disease. Although it provides an initial look at the burden, the data used were often extrapolated from studies that were not specific to Parkinson's. It should also be mentioned that the existing information serves as a conservative economic estimate. Future emphasis on measuring the data gaps will lead to a better understanding of Parkinson's.

Parkinson's is a degenerative chronic disease affecting nearly 100,000 Canadians and has long-term implications on the quality of their lives. As a pro-

gressive and degenerative disease, its social and economic impact increases over time for the patient, the family and the healthcare system. In addition to understanding how the disease itself progresses, there is a great need for data on the economic and social burdens the disease imposes.

Parkinson's also represents a higher economic burden for seniors. Its impact on individuals, the social system and the federal and provincial healthcare systems will increase with the aging population. The disease will have implications not only for Parkinson's patients, but also their caregivers, and others providing social support. These social implications are important and growing, but few studies have focused on caregiver

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burden, and the economic and psychosocial impact of this essential and demanding role.

The current economic impact of Parkinson's is approximately \$23 per Canadian per year. This figure represents the potential benefit to society if the prevalence of the disease was reduced. Moreover, emphasizing social support and networks has been shown to increase quality of life, and reduce the mortality rate^(4,5). This will, researchers believe, lead to potential economic benefits to society.

Further Defining the Social and Economic Burden of Parkinson's Disease

To obtain a more accurate picture of the impact of this disease more specific information is needed. Pieces of the puzzle are available, but much is still missing in the following strategic areas:

- Epidemiology – national and provincial incidence and prevalence in Canada, i.e., number of cases
- Medical Information – continued clinical and biomedical research to understand better the mechanisms of the disease
- Burden for the Individual:
 - greater understanding of the enormous cost of drugs to treat the disease
 - cost of lost income
- Burden for the Family (Caregiving):
 - identification of caregiver(s), and how much social support is being accessed
 - out-of-pocket costs
 - the value of lost work and leisure time

Initiating new partnerships and building on existing ones among the spectrum of those involved with Parkinson's will be essential to clarify what information is currently available and what is missing.

- psychosocial costs
- the positive impacts of networking and social support to patients.

These are just a few examples. Much work remains to be done.

Achieving the Goal

Initiating new partnerships and building on existing ones among the spectrum of those involved with Parkinson's will be essential to clarify what information is currently available and what is missing. Governmental and non-governmental organizations, researchers, academia, people with Parkinson's and their families and caregivers, etc. can then work together to ensure that the gaps in data are filled. As biomedical, clinical, social and

population research produces greater understanding of the impact of Parkinson's disease, these tools would allow health professionals and decision makers to build adequate and appropriate health policies. This, in turn, would assist people living with Parkinson's and their families to better cope with the disease. Ultimately, the result of this would be more efficient use of the Canadian health system and resources, and an increase in quality of life for people living with this disease and their loved ones.

For more information about Parkinson's disease, or to find out more about local resources, contact **Parkinson Society Canada, 4211 Yonge Street, Suite 316, Toronto, Ontario M2P 2A9**; dial **1-800-565-3000**, or visit www.parkinson.ca.

For a complete copy of the Economic Burden of Illness in Canada, 1998, visit <http://www.hc-sc.gc.ca/pphb-dgspsp/publicat/ebic-femc98/> or contact **Health Canada** at **613-957-2991**.

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A better understanding of the full impact of Parkinson's will ultimately result in better and more efficient use of the Canadian health care system and improved quality of life for people living with Parkinson's.

Parkinson Society Canada is the national voice of Canadians living with Parkinson's. Our purpose is to ease the burden and find a cure through research, education, advocacy and support services.

Ease the Burden; Find a Cure

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